VICTORIAN COUNCIL FOR CIVIL LIBERTIES

14 August 2009

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Dear Primary and Ambulatory Care Division,

Re: Healthcare Identifiers and Privacy

Thank you for the opportunity to comment on the above discussion paper.

The contact person for this submission is Tim Warner, Liberty Victoria Committee member. Tim may reached via email on twarner@accesscardnoway.net or via phone on 0408 321 948.

Liberty Victoria would also like to thank Rhys Michie for his contribution to this submission.

Yours Sincerely,

Michael Pearce SC
President
Liberty Victoria

Healthcare Identifiers and Privacy:
Liberty Victoria's Submission

1. Introduction

1.1 The Victorian Council for Civil Liberties Inc—Liberty Victoria— (Liberty) is an independent non-government organization which traces its history back to the first civil liberties body established in Melbourne in 1936. Liberty is committed to the defence and extension of human rights and civil liberties. It seeks to promote Australia's compliance with the rights and freedoms recognised by international law. Liberty has campaigned extensively in the past on issues concerning human rights and freedoms, democratic processes, government accountability, transparency in decision-making and open government.

1.2 In July 2009 the Australian Health Ministers' Advisory Council released a Discussion Paper on proposals for legislative support regarding Healthcare Identifiers and privacy. Liberty has a considerable interest in the privacy implications of the proposed establishment and implementation of national Healthcare Identifiers and enhanced arrangements for the privacy of health information. Liberty recognises the potential benefits of changing how information is accessed and shared across the healthcare system through electronic communication and information technology described as e-health. We are however, cognisant of the privacy implications of the full potential not being realised and the possibility that function creep could extend the use of Healthcare Identifiers beyond their original purpose.

1.3 PROPOSAL 18 & 19 - No question associated with these Proposals:
The fact that no consultation question was provided to comment on the ongoing governance of the IHI scheme is evidence of the very points Liberty made in (2.4 & 3.1) - the committee structure (COAG) simply doesn't allow for the public view and interested groups to be heard as a matter of right. The scheme should have its own described methods of change, preferably through a timed legislative framework, rather than ad hoc regulatory changes driven by an unanswerable secretariat to a Council of Ministers.

The statement that "it is anticipated that some expansion of the proposed HI service may be required[1]" sounds innocuous, but is a key privacy and governance issue.

Inclusion of these proposals in the Discussion Paper telegraphs the intentions of the government to expand the functions of the health identifiers. Thus giving rise to the defence that the public was informed and that the government was open and transparent. The Discussion paper does not explicitly limit expansion beyond health. It provides that:

> "The expansion may be of:
> - the features of the HI Service, e.g. data fields, search features
> - the authorised uses of the HI Service, such as for other purposes related to healthcare or

[1] Discussion Paper - A.6.2.1 Strategic Oversight

- authorised users, to enable new agencies or organisations to use the HI Service."

Proposal 19 provides that should the government decide to expand the function, potentially beyond health, the only requirement is to undertake a privacy assessment (which can be disregarded) and seek agreement from all state and territory ministers (but not gain their agreement). Based on the information provided in the Discussion Paper it is foreseeable that health identifiers could be used as a national ID.

2. Liberty Victoria conclusions

2.1 Liberty is in favour of patient records harnessing modern storage and transmission techniques to improve patient outcomes. Such an improved system will require some method of harmonisation. Common standards for data, agreements as to protocols for data exchange are at the heart of any such system. These are the very items treated as after thoughts in this Discussion Paper. National identifiers have been on the civil services wish list for many years - The Australia Card, The Access Card. It would indeed simplify the life of the bureaucrat - but at enormous loss of privacy and a standing future risk to other liberties.

2.2 In conclusion - the consultation process is inadequate, the proposed legal changes are worrying, the administrative structure is profoundly flawed and the constant refrain that planned future measures will be dealt with after implementation is an admission of a serious failure in public policy process.

3. Process

3.1 Serious problems with the process that has been undertaken in seeking community consultations significantly impede Liberty and other interested parties from maximising this opportunity to participate in this consultative process. It is of great concern that the time frame for a large and complex issue is short. Liberty submits that the interests of the Australian public are being undermined by insufficient time for interested parties to consider the issues and prepare responses. We acknowledge a degree of forewarning of the timetable to some interested parties immediately prior to the release of the Discussion Paper, however if genuine community consultation was a goal of this process, it would be prudent to provide a longer period of time for interested parties to develop our submissions.

3.2 Liberty submits that the nature of this consultation is flawed. Consideration of many important issues has been deferred until first implementation has started. It would be preferable to consult with the community and take decisions prior to implementation. Furthermore, such a process would be cheaper, more transparent and accord with best practice.

3.3 Insufficient information has been released. Important information necessary for consultation and discussion has not been made available within the timeframe. Had the

Privacy Impact Assessment and the analysis of the pilot schemes been made available, a more considered and informed consultation process could have occurred. Liberty submits that our responses to the proposals are not as richly informed as could have been the case had a greater wealth of information been made available during the consultation period.

3.4 The decision not to release submissions to the consultations is incongruent to open and transparent government. As this is an inter-government program, there arises the potential for direct accountability to become unclear. Public comment acts as a check, which is hindered by a lack of transparency. Rigorous scrutiny and participation in the consultation process is necessary to maintaining public confidence. In aggregate, the short timeframe, the deferment of consideration of issues until after implementation, the lack of information and the lack of transparency diminish the consultative process.

3.5 The actual case for the e-health IHI seems to be taken 'as read' - the evidence presented backing the need for an immediate comprehensive national health identifier is as follows: A fifteen year old UK study of 170 referrals in the British system[2] - which has significant operational differences to the Australian medical system. A claim 25% of a clinician's time is spent collecting history from a fourteen year old UK study[3]. Finally, a Paper prepared by a leading database provider - that the patient outcomes are poor without a bigger better database[4]. If the purpose of this paper was to show the need and how it was to be met, then this paper falls significantly short of showing what need is to be met in a federated Australia in 2009. There is also a distinct lack of argument as t how the need (not proven) can only or is best met by the solution suggested.

3.6 It has been noted by other interested groups that the claims that an IHI type system would solve the problems suggested by the papers cited is in fact a misapprehension[5]. Human and technical errors will continue, the difference between the two levels of error bare examination - and are the sort of data set that full analysis of the present trial in NSW may provide. This reinforces the point four above regarding open and transparent information and process.

3.7 Liberty has identified significant privacy concerns with the proposed system. First, although the Discussion Paper clearly explains the operation of Health Identifiers, the delineation of limitations of the system are not concrete. Liberty takes the view that the structure of the system potentially allows for the use of Health Identifiers for purposes not primarily for healthcare. We acknowledge that limited secondary and even a degree of ancillary uses for Healthcare Identifiers may be necessary. However, our concern is that over time, incremental function creep could develop. This raises significant privacy

[2] Discussion Paper A2 p.20 citing -GJ Elwyn & NCH Stott, Avoidable Referrals? Analysis of 170 connective referrals to secondary care, BMJ 309, 3/9/1994

[3]Discussion Paper A2 p.20 citing - Audit Commission, For Your Information: a study of information management and systems in the acute hospital, London, HMSO (1995)

[4] Discussion Paper A2 p.20 citing - Thom Rubel, Electronic Health Information: The Key to Evidence-Based Medicine and Improved Patient Care, Government Insights White Paper, sponsored by BEA/Oracle, October 2008, p.6

[5]Australian Privacy Foundation - APF submission to NeHTA on UHI Blueprint (March 2007) - Section 2.1.1 - from privacy.org.au accessed 13 Aug 09

concerns. The Discussion Paper has not canvassed the future uses of the system, nor how potential extensions of Healthcare Identifiers beyond the initial proposal are to be mitigated. In light of the size of the reform and apparent depth of the capabilities of the technology, the evidence contained in the Discussion Paper does not support the limited application of Healthcare Identifiers.

4. Governance

4.1 As mentioned above (2.4) the nature of the COAG process and the measures outlined in the Discussion Paper have inherent weaknesses. These should be met in the original design of any system. Strict constraints are necessary, not just from a privacy viewpoint, to ensure that accountability is maintained. Sunset provisions, regular open reviews of the system and its arrangements are an essential part of any inter-government arrangement which will have carriage of direct to public services. Public confidence can only be maintained by the highest possible standards of privacy.

4.2 The link between Medicare and the new IHI is unclear in the Discussion Paper. Whilst initial carriage of the administration is through Medicare and its CEO it is implied that this is not the final arrangement. Neither the initial arrangement nor the blue sky approach is equal to the demands required of this proposed system. A key function creep to be guarded against is the use of the 'enhanced data' for purposes other than treatment and (in carefully controlled terms) research and policing. Having the nation's largest health insurer also in charge of patient records is an appalling risk to be built into the system. The present suggest arrangement, for a single IHI field to be added to records, is patently an interim step to a searchable database, and Medicare will patently be the provider of the infrastructure in this scheme. The key role played by Medicare in the failed Access Card is not a hopeful sign as to Medicare commitment to restricting the scope of the IHI.

4.3 The rush to implement the proposed scheme, ahead of key changes and reports on privacy. The issuing of the Discussion paper and the proposed legislative timetable - in advance of publication of the analysis of the second trial and without release of PIA's known to have been commissioned by the NEHTA[6] - are all counter to principles of open and transparent government.

DIRECT RESPONSES TO THE DISCUSSION PAPER

Although Liberty has serious doubts about the process and the governance issues inherent in the scheme outlined, Liberty takes this opportunity to provide further comment and feedback regarding the proposals contained in the Discussion Paper.

Part A

[6]Dearne, K., Secret Report reveals e-Health findings, The Australia n - IT, 4th Aug 2009

Q1. Do you agree that the functions to be conferred on the Medicare CEO are sufficient?
This question assumes that establishing a HI service is acceptable to the Australian community. Liberty questions this assumption. Are there not reservations in the community of the use of individually assigned numbers identifying each and every person in the country? Are individuals not justified to be concerned that the government is intending on allocating to them a number? Is the IHI not an identifier that captures almost the entire population? Are individuals not justified to be concerned that an IHI could be a national ID? Apart from the Tax File Number and proposals for actual national ID cards, is this not the most significant proposal for a comprehensive national identification product? Are individuals not justified to be concerned that information they provided to Medicare will be used for purposes for which they were not explicitly informed at the time they provided the information? Are individuals not justified to be concerned that they have not explicitly consented to Medicare using their personal information to allocate an IHI? Is there not a nominally small number of individuals in this country who actually understand what an IHI is? Is there not a majority of people who would be allocated an IHI who do not have an informed understanding of the IHI? Are individuals not justified to be concerned that the IHI may in the future be used for purposes outside the health system? Are individuals not justified to be concerned about technical security aspects of centralised e-health system? Liberty submits that prior to supporting Proposal 1 the concerns raised above should be addressed.

Furthermore, Liberty submits that function creep is a legitimate concern. Are individuals not justified to be concerned about function creep? Where in the Discussion Paper have core mechanisms for preventing function creep been discussed? What legislative proposals address function creep? What legislative proposals prohibit use outside the e-health system? Are future governments not bound by undertakings made by previous governments? Given that the IHI is being introduced by a government legislating for the use of information for a purpose different to the purpose for which individuals provided that information to Medicare, are individuals not justified to be concerned that future governments may legislate to use health identifier information for a purpose outside the e-health system at another date? Where in the Discussion Paper are legislatively entrenched mandatory reviews proposed?

As with so many of the Proposals and Questions, the ability to answer Question 1 clearly is impeded by a lack of clarity in the intended use and operation of the IHI system. It would be prudent to start with a clearly bounded new system, and then have future debate about properly prepared and argued changes. Instead an overwhelming appeal to trust of the motives and aims is substituted for careful consideration of here and now discussion of the practical uses of the powers and exceptions being granted

Q2. Are there significant issues raised by regulating the handling of healthcare identifiers by public and private health sector organisations through existing privacy and health

information laws with some additional regulatory support through specific enabling legislation for healthcare identifiers?
Liberty submits that there has not been sufficient discussion of complaint handling mechanisms. Having access to simple complaint handling mechanisms is important in the context of the health sector. Are individuals not justified to be concerned that provisions for a complaint handling mechanism have not been explicitly stated in the Discussion Paper? In tandem with a complaint handling procedure, audit and oversight procedures instil trust in the system. Liberty submits that there has not been sufficient discussion of audit and oversight mechanisms. Are individuals not justified to be concerned that the mechanisms for privacy complaints have not been explicitly and clearly canvassed in this Discussion Paper? Where in the Discussion Paper is the 'How to lodge a complaint' process described?

Q3. Are there circumstances where penalties for misuse of a healthcare identifier and associated information that is held by a healthcare provider will be inadequate?
Liberty holds the view that uniformity of privacy law across the jurisdictions provides clarity and promotes conformity. Situations where penalties for misuse vary between jurisdictions should be harmonised.

Q4. Is it appropriate that definitions contained in privacy law are adopted?
Liberty holds the view that definitions of healthcare service and healthcare service provider should be included in the legislation and that consistency of definitions between legislation provides clarity. We support the definitions recommended by the ALRC.

Q5. Are there other specific terms that should be defined?

Q6. Do the limits on disclosure set out in Proposal 4 provide adequate protection for an individual's personal information?
Liberty supports the limits on disclosure set out in Proposal 4. Given the capacity of information technology to send and receive information using identifiers known only to the administrator level of the software. It would seem unnecessary to have regular access to the patient IHI. A log of request for the matching of IHI and patient personal details could then be kept to supervise and audit the use and misuse of the IHI by service providers and their agents.

Q7. Is the authorisation for healthcare providers set out in Proposal 5 required to provide certainty to healthcare providers, noting that the use or disclosure could occur under existing privacy arrangements as a directly related and reasonably expected secondary use or disclosure of health information?

The generation of electronic referrals, the sending of electronic prescriptions and the sending and receiving of pathology data could all be done without human awareness of the IHI. This should only be requested by operators if a real doubt existed as to the patient data match. To this extent, Liberty is limited in its support for Proposal 5.

Q8. Does the limit on disclosure set out in Proposal 6 provide adequate protection for a healthcare provider's personal information?
The protection provided by the Health Insurance Act is an appropriate level for this purpose. It would be preferable for the proposed legislation to be contained in the Discussion Paper. Liberty supports Proposal 6.

Q9. Does the proposal to apply secrecy provisions similar to those set out in the Health Insurance Act or the National Health Act provide sufficient protection for personal information held by the HI Service Operator?

Liberty submits that the secrecy provisions should be in harmony where possible with those levels required by the operator agency. The level of damage is equivalent and therefore there should be consistency of penalties.

Q10. Is there a need to apply a specific penalty to unauthorised use or disclosure of healthcare identifiers by health sector or other participants who hold the healthcare identifier in association with health information?

Liberty submits that the creation of a specific penalty for unauthorised use or disclosure of healthcare identifiers would promote compliance and enhance public trust in the proposed system. Liberty holds the view that consistency of penalties between legislation provides clarity and promotes conformity. The *Health Insurance Act 1973* or *National Health Act 1953* provide appropriate models to be followed. Liberty advocates that administrative and civil sanctions are appropriate penalties for minor breaches, whereas serious breaches involving intentional or reckless use or disclosure should attract criminal sanction.

Q11. Do you agree that existing health information regulation and administrative arrangements will provide sufficient secondary use requirements for organisations handling healthcare identifiers?

Liberty supports Proposal 9. The existing authorised secondary use provisions are adequate, the Privacy Commissioner's guidelines should be promoted to provide clarity and promote conformity.

Q12. Do you agree that existing health information regulation and administrative arrangements will provide sufficient data quality requirements for organisations handling healthcare identifiers?
Liberty supports Proposal 10.

Q13. Do you agree that existing health information regulation and administrative arrangements will provide sufficient data security requirements for organisations handling healthcare identifiers?

Data security is essential to community support. Protection from misuse, loss or unauthorised access should be set at standards as high as practicable. Liberty advocates for a system of audits and oversights, in tandem with a complaints handling procedure to instil

trust. Liberty supports Proposal 11 to a limited extent; a more rigorous standard would be preferred as would a complaints handling procedure.

Q14. Do you agree that existing health information regulation and administrative arrangements will provide sufficient openness requirements for organisations handling healthcare identifiers?

Open and transparent government are endorsed by Liberty, as such we support Proposal 12.

Q15. Do you agree that existing health information regulation and administrative arrangements will provide sufficient access and correction capability for individuals?
Access and correction are endorsed by Liberty supports the utilisation of Medicare's processes for access and correction contained in Proposal 13.

Q16. Will the proposals to overcome current identifier restrictions on private healthcare providers effectively enable participation in the HI Service?

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Q17. Do these proposals raise any significant issues in relation to the handling of identifiers?

This issue of the visibility of identifiers is a major concern in the administrative arrangements proposed. Liberty does not see why the IHI should be so visible to all participants at all times. If the access to the identifier were restricted a major day to day risk to privacy could be reduced. Outside the scope of this question is whether the IHI is even necessary to undertake many of the most patient positive steps in electronic health provision.

Q18. Do you agree that existing health information regulation and administrative arrangements will provide sufficient anonymity requirements?
Liberty advocates for the ability for individuals to conduct transactions with healthcare services anonymously or using a pseudonym where it is lawful and practical. It would be preferable for the arrangements to align with emerging international standards. Liberty supports Proposal 16.

Q19. Do you agree that existing health information regulation and administrative arrangements will provide sufficient requirements for transborder data flows?
Liberty advocates for uniformity of privacy law across jurisdictions. In the absence of uniformity, and operating on an assumption that this is a goal which COAG is working towards, Liberty supports in Proposal 17 in principle.

Q20. Does this proposal raise any significant issues in relation to the handling of identifiers?

This proposal is an ad hoc solution, arising in part because the structure of the e-health system is being introduced without the necessary legislative arrangements being in place. If COAG were not to introduce uniformity of privacy laws within a reasonable period of time, Proposal 17 would not be appropriate. Liberty submits that a sunset clause should be introduced, giving a finite period of time (3 years for instance) for harmonisation of privacy laws to occur.

Q21. Do you think participation agreements are an appropriate mechanism for setting out the responsibilities of the parties involved (i.e. healthcare provider organisations and the HI Service Operator)?

Liberty supports Proposal 20. Establishing participation agreements is an appropriate mechanism for setting out the responsibilities of the parties involved.

Q22. If so, do you consider that legislation is necessary to underpin the participation agreements?

Liberty advocates for legislation to underpin participation agreements. This would represent best practice.

Part B

Q23. Are there any other requirements that should be specified in legislation?

A guaranteed timetable in any originating legislation – for an independent review after fixed time – say three years. This would allow for both administrative best practice and public confidence to be maintained.

Q24. Is it necessary that arrangements for and enforceability of directions or guidelines that are jointly agreed by privacy regulators to be supported by legislation?

Liberty agrees with the ALRC that existing Commonwealth and state and territory regulators should be responsible for ensuring compliance with the privacy framework and enforcing compliance. We agree that national coordination is necessary to ensure consistency of compliance and enforcement of the national framework. Our position is that legislation is necessary to support the enforceability of directions or guidelines. It is in our view that administrative or civil penalties are appropriate sanctions for breaches of the law by agencies or organisations. The directions or guidelines of privacy regulators should hold a paramount position in order to maintain the trust of the public. Absent appropriate sanctions for breaches, the directions or guidelines of the regulator lose their weight, the regulator becomes a toothless tiger and there is no reason why the public would have faith that agencies and organisations would respect privacy considerations.

Q25. Are there any reasons for the privacy of health information about deceased persons to be treated differently to other personal information about them?

Liberty concurs with the ALRC's view that the national framework should apply to personal information of deceased persons. We submit that there should be consistency of privacy protection for personal information of deceased persons and that privacy law is the appropriate instrument.

Q26. Is the proposed definition of health service provider appropriate?

Liberty supports clear and concise definitions to bring clarity and certainty. The definition of service provider in Proposal 24 is almost circular. It would be preferable for a different definition to be developed

Q27. Are there any other terms that need to be defined to support a health information privacy protection as part of a national framework?

Q28. Do you agree that the amendments proposed above are appropriate?

Liberty supports the ALRC's recommendation for UPPs. The uniformity of the principles encourages consistency across whole of government. Where necessary and appropriate, the proposed health specific requirements and modifications as recommended by the ALRC are supported by Liberty. We support Proposal 25; however it should be made clear that the amendment is to allow the collection of sensitive information where there is a serious threat to an individual's welfare, *to provide for their welfare.* Liberty provides in principle support to Proposal 26 (of the face of it). Insufficient information has been provided to make a conclusive judgment. It would be preferable that the grounds for the initial inclusion of the exception and persuasive arguments for its deletion be provided before Liberty is willing to provide concrete support for this proposal. Liberty supports Proposal 27 and believes that it is prudent that other appropriately qualified individuals or organisations in the field of research be conjoined with the Privacy Commissioner in developing guidance in relation to the collection of sensitive information necessary for research purposes. The stated requirement that the collection meet specific conditions, including (but not limited to) the purpose cannot be served by the collection of information that does not identify the individual and it is unreasonable or impracticable to seek consent. Similarly, we support Proposal 28 and submit that this represents prudent practice. Furthermore, Liberty advocates that such rules should be binding and that administrative or civil penalties are an appropriate sanction promoting conformity and compliance.

Q29. Are there any other circumstances where the collection principle might require amendment in relation to health information?

If a particular requirement that has not been addressed in the original legislation changes this could be part of a review of the entire scheme after a fixed time period.

Q30. Do you agree that the amendments proposed above are appropriate?

Liberty supports Proposal 29; however, similar to our response to Question 28, we advocate that it should be made clear that the amendment is to allow the collection of sensitive information where there is a serious threat to an individual's welfare, *to provide for their welfare.* Consistent with our response above Liberty supports Proposal 30, again endorsing the stated requirement that the collection meet specific conditions. We support the further additional requirement that the collection must comply with any guidance issued by the Privacy Commissioner. This acts as a safeguard, enhances accountability and represents best practice. Liberty supports Proposal 31, consistent with our remarks made above; we submit that this represents prudent practice and that administrative or civil penalties are an appropriate sanction promoting conformity and compliance.

Liberty supports the proposal to allow personal information to be used or disclosed where a person is known to be missing contained in Proposal 32. However, where a person is known to be deceased, it seems unlikely that disclosure such information is necessary in assisting a law enforcement officer ascertain their whereabouts. Furthermore, Liberty advocates that the proposed exemption be amended to apply to persons *reasonably* suspected to be missing or deceased. This would provide an objective test which would give decision makers greater certainty and clarity. Liberty acknowledges that the limitation to circumstances where the use or disclosure is not contrary to any wishes expressed by the individual before they went missing or became incapable of consenting and that it would be limited to a law enforcement officer for the purposes of ascertaining the whereabouts of the person provides an appropriate check. Liberty notices that capacity to consent has not been explicitly addressed in this question and that the IHI would apply to all persons. A degree of latitude should be incorporated to address situations involving minors or persons lacking mental capacity.

Liberty supports the ALRC's proposal to allow health services to provide health information about an individual to a person responsible for an individual. Expanding the scope beyond intimate relationship to include persons who have a personal relationship and from primary responsibility to responsibility for providing support or care is appropriate. This provides latitude and meets the needs of health care consumers. In Liberty's view, guidelines identifying relationships with sufficient degree of intimacy or responsibility would offer a more flexible approach than an inclusive list and is more consistent with the purpose of the Proposal 33.

Q31. Are there any other circumstances where additional guidance about the use or disclosure of information would be helpful?

Reasonableness test possibly a fixed mechanism for the query – through Privacy official or other legal or statutory official of independent status

Q32. In relation to Proposal 32, should an agency or organisation be required to have a reasonable expectation that the person responsible for the individual will act in the best interests of the individual in receiving that information? Would guidelines provide sufficient certainty?

Liberty submits that a reasonable expectation that a person responsible for the individual will act in the best interests of the individual in receiving that information is an appropriate safeguard that should be incorporated into guidelines. Furthermore, this would provide decision makers with an objective test, providing clarity and promoting consistency in decision taking.

Q33. Do you agree that the consent of the individual should be obtained for the use or disclosure of health information for direct marketing purposes?

Liberty does not support the ALRC's recommendation that an organisation may use or disclose personal information for direct marketing purposes, provided there is a reasonable expectation. This recommendation is incongruent with privacy. Providing a simple opt out method does not suffice to ameliorate our concerns. Liberty submits that informed consent must be a necessary precondition for the use or disclosure of all personal information, including health information, for marketing conditions.

Q34. Are guidelines sufficient to ensure that health information is retained for a suitable period of time?

This relates directly to the implementation before the scope of the project and its mechanism is fixed. If the scheme is in fact for the availability of complete history – but with no central repository – then storage must be indefinite (or at least for the life of the patient). If the aim is to have immediate records, with no function creep guaranteed, then professional standards might be applied – say seven or ten years of files. If there is a change of scope – then records that are important to implement the larger scheme may be destroyed to the detriment of the intended policy outcome. Similar logic applies to the closure of providers or their merger with other entities. Therefore – what is a suitable time is unknown and unknowable with the information provided to the public.

Q35. Do you agree with these proposals?

Liberty supports Proposal 37. Inserting a note as recommended is consistent the philosophy underling UPP 9 to provide access. Liberty advocates that there should be a presumption of access and that in situations where grounds to refuse access exists, the presumption should operate where appropriate. Furthermore, this proposal would provide clarity to decision makers and represents best practice.

Q36. Are guidelines sufficient to ensure processes for access to health information are understood by agencies and organisations?

Liberty supports Proposal 38, and recommends that the guidelines be upgraded to be rules. This would provide clarity, enhance consistency in decision making and with the imposition of administrative or civil sanctions for breaches, would promote compliance. The greater the detail the more utility there is in such guidelines or rules.

Q37. Are any other amendments to the access principle required?

In light of a movement to remove fees for access to information for Freedom Of Information requests, introduce statutory limitations on the time to respond to requests for information under FOI and a presumption for openness that is occurring in other jurisdictions and may be canvassed by the ALRC in the future, Liberty suggests that these measures be considered as possible future amendments.

Q38. Do you agree with this proposal?

Liberty has concerns with this Proposal for the same reasoning as suggested above, the general visibility of the identifier is a major problem. The expansion of its use and availability cripples any attempt at maintaining privacy of medical data and reducing the availability of key personal data such as address.

Q39. Are any other situations where the identifier principle might have an inappropriate effect on the use or disclosure of health information?

This is where the change from Medicare number to IHI is at its most dangerous from a privacy view point. If all the functions of the health care professionals are to be tagged and accessible under the IHI then this removes the privacy safeguards we have considered the norm under Medicare. At present only the clerk who processes a Medicare claim knows the present health identifier, and this is useless at gathering further information outside of the Health Commission. It is the way in which the IHI is used by health providers that will be the first point at which exposure of private data is risked. It may be necessary to have an access log –with particular reference to reverse searches (the seeking of data by IHI), as this should only occur at first presentation or in limited accounting or audit checks the scale of such a log should not be prohibitive. Given reducing costs of data storage – complete access logs would be best practice. The use of the IHI as a filing identifier or for office use should be prohibited. This is not impossible – as computers used under this system could generate the referrals and place the IHI without the operator having to have the key IHI number.

Q40. Do you agree with this proposal?

Liberty generally agrees with Proposal 40; however we submit that there should be a *reasonable belief* that the use or disclosure will lessen or prevent a serious risk to life health safety or welfare.

Q41. Are there any other exceptions for health information transferred outside Australia?

No.

Concluding Remark on Discussion Paper Response

Liberty Victoria recognises the potential benefits of changing how information is accessed and shared across the healthcare system through electronic communication and

information technology described as e-health. Through this submission we have highlighted some of the privacy implications, short fallings in the proposals, and concerns with the consultation process and expressed our concern that function creep could extend the use of Healthcare Identifiers beyond their original purpose. Whether or not the community accepts and trusts the health identifiers and e-health, will to a degree, depend on the whether the consultative process yields real changes to the proposals.